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Improving Goals of Care Conversations with High Risk Heart Failure Patients

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Improving Goals of Care Conversations with High Risk Heart Failure Patients

A dissertation submitted in partial satisfaction of the requirements for the degree Doctor of Nursing Practice

by

Yichun Michelle Fang

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ABSTRACT OF THE DISSERTATION

Improving Goals of Care Conversations with High Risk Heart Failure Patients

by

Yichun Michelle Fang

Doctor of Nursing Practice

University of California, Los Angeles, 2020

Professor Barbara Bates-Jensen, Chair

Background: Heart failure (HF) is a progressive, chronic disease that can be complicated or caused by pulmonary hypertension (PH). Goals of Care Conversations (GoCCs) are discussions to: identify a healthcare surrogate, initiate and review advance directives, and refer for palliative care consultation. Providers struggle with determining HF prognosis and initiating GoCCs. Gagne Combined Comorbidity Score prognosticates a one-year mortality risk. **Purpose:** Implementation of an electronic prognostication tool, Gagne Score, for clinicians to identify and increase documentation of GoCCs with high-risk HF patients. **Design:** Pre- and Post-intervention quality improvement (QI) project at an ambulatory clinic to evaluate use of a prognostication tool in improving documentation of GoCCs with HF patients. **Methods:** Prior to each clinic, providers notified of high-risk HF patients, identified using prognostication tool. Medical record

data on provider documentation of four aspects of GoCCs: presence and review of advance directives, documented healthcare surrogates, and referral for palliative care consultation, collected for nine weeks pre and post intervention. Demographic and medical data on PH patients treated during pre and post intervention. Demographic, education and experience data collected by survey from provider participants. Descriptive statistics, chi square analysis, and t-tests used to compare documentation of GoCCs pre- and post-intervention. **Results:** Providers were female, specialized in cardiology with 26 ± 8.5 years of experience, including a physician, clinical nurse specialist, and nurse practitioner. No differences existed in age, gender, ethnicity, PH diagnosis, or Gagne Score for patients treated during pre and post intervention. Documentation of GoCCs was significantly greater post intervention compared to pre-intervention (0%, n=0/47 and 88%, n=35/40 respectively, $p<0.001$). Documentation of each of the four aspects of GoCCs was variable with the greatest improvement in documentation of healthcare surrogate and review of advance directives. Referral for palliative care consultation remained low (0%, n=0/47 and 0%, n=0/40). **Conclusion:** Implementation of an electronic prognostication tool using Gagne Score was effective in increasing documentation of GoCCs in 3 criteria of GoCCs: advance directives, healthcare surrogate, and reviewing of previously completed advance directives. Referral for palliative care did not increase with this intervention and indicates an area for improvement.

The dissertation of Yichun Michelle Fang is approved.

Mary Cadogan

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2020

DEDICATION

This is dedicated to my family and friends that have given me the strength and unwavering support to continue through this journey.

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

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BIOGRAPHICAL SKETCH

Yichun Michelle Fang obtained her Bachelor of Science in Nursing from New York University. She completed her Master of Science in Nursing at the University of California – Los Angeles. She is a board-certified nurse practitioner, with a passion in working with the vulnerable population.

Introduction

Heart Failure (HF) is a progressive, chronic disease that primarily affects the aging population. More than 6 million Americans are estimated to have HF with an expected 46% increase by 2030 to greater than 8 million people (American Heart Association [AHA], 2019). Despite advancements in HF therapies, almost 40% of patients die within the year following the first hospital admission, and half within five years of diagnosis. (Liu & Eisen, 2014). Currently HF accounts for 1 in 8 deaths in the United States (AHA, 2019). The Agency for Healthcare Research and Quality [AHRQ], (2017) found HF to be the leading cardiovascular diagnosis for hospital inpatient stays. In 2012 the overall cost of HF was estimated at $30.7 billion, with a projected increase of 127% by 2030 to $69.8 billion (AHA, 2019). The main portion of spending is associated with hospitalizations, followed by diagnostics, pharmacotherapy, devices, and chronic disease management programs (Groeneveld et al., 2019).

There are many etiologies for HF, such as Pulmonary Hypertension (PH), a chronic disease that affects the arteries in the lungs and the right side of the heart. Conversely, PH is also the most common complication for patients with HF. The World Health Organization (WHO) identified five different PH groups based on etiology: pulmonary arterial hypertension, PH with left heart disease, PH with lung disease, PH associated with chronic thrombi in the lungs, and idiopathic PH (Ryan, et al., 2012). There is no cure for PH, a disease that primarily affects women, non-Hispanic blacks, and individuals 75 years and older (Centers for Disease Control and Prevention [CDC], 2019). The incidence of PH is, most likely, higher than estimated due to limited information on demographics and clinical course (European Society of Cardiology [ESC]/European Respiratory Society [ERS], 2015). The overall prognosis for PH is poor with an estimated 15% mortality within one year of diagnosis and 43% mortality within five years,

despite modern therapy (American College of Cardiology Foundation [ACCF]/AHA, 2009; Benza et al., 2012). For patients diagnosed with PH, HF is the most common cause of death (U.S. Department of Health and Human Services [HHS], 2019). The estimated annual healthcare cost for PH is approximately $100,000 driven primarily by hospitalizations and medications which is significantly higher than the estimated annual cost of $31,400 for all HF patients (Sikiric et al., 2014; Groeneveld et al., 2019).

Goals of care conversations (GoCCs), are a series of dialogues between the clinicians and patient, to identify the patient's values, goals, and preferences for end-of-life care. Components of GoCCs include: identifying an authorized healthcare surrogate or surrogates, discussing prognosis of medical condition, and ascertaining the patient's values to develop and document a plan for use of life-sustaining treatments or referral for palliative care consultation. The GoCCs also incorporates a review of documents reflecting the patient's wishes, such as advance directives or state-authorized portable orders (Saiki et al., 2017). When GoCCs do not occur prior to a health crisis, patients with serious illnesses may not have the opportunity to indicate their preferences for life-sustaining treatments. All patients with a high risk of dying within the next one to two years should be considered for GoCCs (Lakin et al., 2016).

In the United States only one third of adults have a completed advance directive, with even less amongst seriously ill patients (Yadav et al., 2017). In the Late Life Survey conducted by the Kaiser Family Foundation (2017), 80% of people responded that if seriously ill they would prefer to talk to their doctor about their wishes for end of life medical treatment however, only 18% had this conversation. Of the 34% with written documentation of their preferences, only 10% had shared it with their providers. The Conversation Project, a national survey conducted by the Institute for Healthcare Improvement [IHI] (2018), found that 92% of

respondents agreed talking with their loved ones about end-of-life care was important, but only 32% had actually done so. This lack of communication results in a transfer of decision-making burden onto healthcare surrogates, who are usually uncertain about the patient's preferences. Documenting life-sustaining preferences elicited from GoCCs, can reduce hospitalizations, increase likelihood of clinician and family compliance with patient wishes, reduce aggressive medical care at end of life, and increase the utilization of hospice (Rose et al., 2019; Brinkman-Stoppelenburg et al., 2014).

Heart Failure patients are at risk for rapid unexpected shifts in clinical status, and sudden cardiac death, therefore the Heart Failure Society (2014) recommends clinicians to integrate GoCCs and prognosis early, to support patient-centered care. Patients with documented GoCCs prior to a medical crisis have demonstrated significantly lower health care costs without an increase in mortality (Zhang et al., 2009). Despite all of this, the unpredictable trajectory of HF has made it challenging for clinicians to determine prognosis and identify "high-risk" patients with whom to initiate GoCCs. Standardized mortality prediction models have been suggested as a tool to risk stratify patients, identifying those with the highest mortality to be targeted for GoCCs (Buggey et al., 2015). The ACCF and AHA Heart Failure Guidelines (2013) support the use of multivariable risk scores by clinicians to estimate risk of mortality in ambulatory patients with HF. The American Geriatrics Society (2012) also recommends the use of validated tools to predict mortality. The University of California, San Francisco e-prognostication site (eprognosis.ucsf.edu) is recommended for identifying an appropriate prognostic index based on demographic characteristics, diagnoses, and functional status. Per this database, patients living at home and in the United States, the Gagne Combined Comorbidity Score is recommended for estimating one-year mortality risk (Kim & Rich, 2016; Lum & Sudore, 2016).

Given the evidence supporting GoCCs in improving end of life care, the goal of this evidence-based quality improvement (QI) project was to increase GoCCs initiated by clinicians with high-risk HF patients, identified risk with one-year mortality with the Gagne Combined Comorbidity Score. Two research questions were identified for this study:

1) Does pre-identification of high-risk patients (Gagne Combined Comorbidity Score 3 or higher) and a pocket sized GoCCs communication guide, prompt clinicians to initiate and document GoCCs?
2) If GoCCs are documented, how many components of GoCCs are addressed: authorized healthcare surrogate(s), presence of advance directive, review of previously completed advance directive, or referral or consultation for palliative care?

Theoretical Framework

Bandura's Social Cognitive Theory is a framework that evaluates the interaction between personal factors, behavioral factors, and environmental factors, to influence behavior change (Bandura, 1986). This theory examines the intervention needed to spur the behavior change needed in clinicians, to address goals of care with high risk patients. Personal factors address the clinician's knowledge of, expectations of, and attitudes towards GoCCs. This includes clinician demographics, prior experience with and knowledge of GoCCs, and their agreement with the indications for implementing GoCCs into their clinical practice. Clinicians may have had prior observations or personal experiences that led to a positive outcome which may predispose them to incorporating GoCCs into their clinical practice. All of these factors can influence the clinician's evaluation of the potential risks versus benefits, and opportunities versus limitations, and change their behavior accordingly (Bandura, 2001).

Environmental factors influence a behavior change by establishing an atmosphere that has adequate tools and resources to support the behavior (Hearn et al., 1998). Potential environmental factors affecting clinicians include ease of charting, allotted time for each visit, experiences from fellow colleagues with GoCCs, the patient's experience with GoCCs, and healthcare facility initiatives to encourage initiation of GoCCs. The behavioral factors component involves the skills, practice, and self-efficacy needed to influence the course of action and persistence when confronted with obstacles (Sheeshka et al., 1993). From the clinician perspective this includes previous education to develop the skills to initiate a GoCCs with questions and conversation openers. Clinician behavioral factors are essential in supporting Shared-Decision Making between patient and clinician with GoCCs.

The Shared-Decision Making Model is a clinical practice model that supports clinician and patient collaboration in identifying preferences and values for future medical care. It is a clinical practice model that supports clinicians in sharing best available evidence with patients when tasked with making decisions and considering options for identifying informed preferences. It is founded on the principles of patient-centered care creating a process where clinicians and patients formulate a care plan that is based on evidence while balancing the risks and expected outcomes against the patient's preferences and values (Stiggelbout et al., 2015). It incorporates the self-determination theory that all beings have intrinsic tendencies to protect and preserve our well-being; and the theory of relational autonomy that individual decision making is determined by interpersonal relationships and mutual dependencies (Elwyn et al., 2012).

The Shared-Decision Making Model is comprised of three main concepts: introducing choice, describing options, and helping patients to explore their preferences. This process requires at least two participants, the clinician and the patient. In the clinical setting it is usually

more complex involving other clinicians/specialists or family and friends. Involving the patient in decision-making requires the clinician to create an environment for the patient to feel that their opinion is valued and important, to elicit the patient's preferences so appropriate options can be presented, to transfer the technical medical information in an unbiased format at the appropriate learning level, then to assist the patient in weighing the risks versus benefits of the options presented. The Shared-Decision Making Model allows the patient to assume some or all decision-making control while allowing the clinician to go beyond just providing information, to participating in, not dominating, the decision-making process (Charles et al., 1997). Within the context of high-risk HF patients, shared decision-making is accomplished by helping the patient and/or family to understand the severity of the chronic illness, and exploring the patient's preferences for goals of care with life-sustaining treatments, to reach a consensus on a future medical treatment plan.

Review of Literature

The literature search was completed on the PubMed, Science Direct, and CINAHL databases. Given the strong correlation of PH with HF, the literature search focused on evaluating the role of prognosis and goals of care with HF patients. The search encompassed three terms: heart failure, prognosis, and goals of care, which resulted in 395 results on PubMed, 23 results on CINAHL, and 781 results on ScienceDirect. Next, additional parameters were instituted to limit studies to adult human research from the past five years, published in English journals with full text available, and research articles only. This reduced the search to 125 results on PubMed, 2 results on CINAHL, and 19 results on Science Direct. Following the removal of six duplicates, the abstracts of the remaining 140 results were reviewed for relevance. All studies performed in the inpatient, emergency department, hospice, nursing home settings, and pediatric

studies were removed. Also published research protocols, guidelines, and studies not related to HF were removed. The full text from the remaining 30 studies were evaluated for relevance. The focus of this literature review was to identify original research studies therefore all systematic reviews, narrative reviews, and meta-analysis studies were removed. Remaining articles with no relevance to goals of care discussions or prognostication with HF patients were also removed. The remaining ten studies were subjected to further review. These articles evaluated the barriers to initiating GoCCs with HF patients, the benefits of initiating GoCCs with HF patients in the outpatient setting, and the evidence to support the utilization of prognostication to aid clinicians in initiating and documenting GoCCs with high-risk HF patients. A focused search was performed for literature regarding the use of prognostication tools for HF patients, and original research on the development of the Gagne Combined Comorbidity Score. These additional three articles provide foundational information for the utilization of the prognostication tools for identifying high-risk HF population (see Figure 1).

An additional literature review was conducted to evaluate available research for the proposed intervention. The first search was conducted on PubMed and CINAHL using the search terms: reminders, and goals of care. This generated 293 results, that was reduced to 80 results after implementing the filters: English language, full text available, and published within the past 5 years. The abstracts were reviewed for relevance to a provider/clinician-focused intervention resulting in a change of behavior. The full text of two articles were reviewed and included for further review. Another search on PubMed and CINAHL utilizing the search terms: clinician intervention, and advance care planning, generated 100 results. This was reduced to 60 results after the filters: published within past five years, full text available, and English language. The abstracts were, reviewed for relevance to a provider/clinician-focused intervention resulting in a

change of behavior. There were no results, however a relevant systematic literature review was identified. The full text was reviewed for additional search terms, and the references reviewed for additional research articles. One article from the initial literature review was a duplicate and two additional articles were identified for further review. The five research articles identified for further review were focused on evaluating the effects of a clinician-targeted intervention to engage clinicians in changing their clinical practice.

Synthesis of Literature

The Shared-Decision Making Model highlights the importance of patient engagement therefore it is important to evaluate the patient's perspective in developing an understanding of barriers associated with initiating of GoCCs. Several qualitative studies support that patients are interested in and open to discussing goals of care, but are waiting for their clinicians to initiate these discussions. A qualitative study of a cohort of 65 years and older HF patients, evaluated their perception of HF and the needs associated with HF at the end of life, found that there was poor understanding of the disease and prognosis (Klindtworth et al., 2015). Further investigation revealed that patients relied heavily on their clinicians to provide them information regarding their disease and prognosis. Additional qualitative studies also found that there was a variation in patient response with how and what information they wanted from their clinicians (Hjelmfors et al., 2018). Two common themes were identified, firstly HF prognosis was not being addressed during interactions with clinicians, and secondly when the prognosis was presented in an overall optimistic manner it did not fully convey the severity of the patient's diagnosis. At baseline researchers also found a discrepancy in the physician versus patient perceptions of the prognosis of HF. While most providers identified the majority of patients to be at risk of worsening HF, less than a quarter of the patients perceived their disease to be life-threatening. In addition to

under estimating the severity of their disease, patients also over estimate their prognosis (Ambardekar et al., 2017). Despite this misunderstanding, the majority of patients had considered goals of care, especially identifying a surrogate decision maker, but had not shared this information with their clinicians (Gordon et al., 2017).

Within the Shared-Decision Making Model, clinicians are an essential component of providing patient-centered care therefore it was important to examine the barriers that clinicians encounter in initiating GoCCs with their high-risk HF patients. The most common barrier was related to patient and their family's responses to accepting a poor prognosis, understanding the potential benefits and harms of life sustaining treatment options, and disagreement regarding identified goals of care (You et al., 2017). Remarkably, it was further noted that, cardiology clinicians, including physicians, advance practice nurses, social workers, and nurses were all willing to engage in GoCCs with patients. In a similar study, evaluating clinicians treating HF and chronic obstructive pulmonary disease, most clinicians agreed it was important to discuss prognosis with patients and to re-evaluate the patient's goals of care with changes in the disease trajectory (Siouta et al., 2018). A review of clinicians' perspectives revealed that while clinicians agreed that palliative services should be offered there was no consensus on when it should be initiated. This variable response was mostly correlated with potential misconceptions about palliative care services and its role in symptom management and quality of life for chronic diseases. Another study by Gadoud et al. (2014) found a significant difference in the utilization of palliative care services among HF patients, in comparison to cancer patients. A third of the HF patients enrolled in palliative care, did not begin receiving palliative care services until one week prior to their death. From the clinician perspective there appears to be consensus that GoCCs should be initiated and prognosis reviewed with the patient, however there continues to be a gap

in actually initiating GoCCs and recognizing the role of palliative care services for high-risk HF patients.

The research supports incorporating goals of care into clinical practice, from both the clinician and patient perspectives, therefore the next step is to evaluate the interventions to prompt clinicians to initiate GoCCs. When systematic processes were implemented within interprofessional teams there was a notable increase in the number of GoCCs and referrals of patients for palliative care services. A randomized control trial of patients with and without palliative care services, found significant clinical benefit to the patients enrolled in the palliative care arm, with reported improvements in quality of life (Rogers et al., 2017). In another study the researchers found that patients enrolled in a comprehensive palliative care program to address psycho-social issues, symptom management, and goals of care resulted in an increase in documented GoCCs and life-sustaining treatment preferences (Wells et al., 2018).

The additional literature review was conducted to further evaluate the significance of a clinician targeted intervention to prompt clinicians to initiate GoCCs with high-risk patients. To assist with initiating GoCCs, Doorenbos et al. (2016) evaluated the effectiveness of identifying high-risk patients, to target with a telephone pre-visit communication regarding GoCCs. This information, in addition to mortality estimates calculated with the Seattle Heart Failure Model and Kansas City Cardiomyopathy Questionnaire, was then shared with clinicians on the day of the scheduled visit. Over the course of the study the number of documented GoCCs between HF patients and clinicians increased from 2.6% to 58%. Similarly, Haley et al. (2016) found that clinicians that received a quick didactic session in addition to electronic reminders also had an increase in documented GoCCs from 20.5% to 44.6%. These findings were similar with other studies that evaluated the role of electronic reminders for clinicians with targeted

high-risk patients to increase documentation of GoCCs, or completed advance directives (Dexter et al., 1998; Karim et al., 2018). A notable increase in documentation of advance directives was seen when the patient received a mailer with information prior to the clinic visit, in addition to electronic reminders for the clinicians (Heiman et al., 2004).

Cumulatively the literature confirms GoCCs are wanted and indicated by patients and clinicians, but barriers are preventing this from occurring. One of the main barriers is determining the prognosis of HF and communicating the information effectively to patients. Interventions that have been studied include integrating palliative care specialists to continue GoCCs following initiation, and also incorporating interprofessional teams to evaluate for high-risk patients and provide patient education. However, none of these interventions can be effective if GoCCs are never initiated. Therefore, using a prognostication tool to identify patients at high risk for mortality within one-year, and a pocket-sized communication guide will assist clinicians in identifying high-risk patients to initiate GoCCs.

Methods

This QI project examined clinician documentation of GoCCs with high-risk HF patients. The proportion of high-risk HF patients who had documentation of a GoCCs pre-intervention, were compared to the proportion of high-risk HF patients who had a documentation of a GoCCs post-intervention. Clinicians were provided a pocket-sized communication guide to initiate GoCCs with high-risk HF patients, identified using an electronic prognostication tool and presented to clinicians prior to clinic visits. Further, the documentation of the presence of the four components of GoCCs pre- and post-intervention were compared. The four components of GoCCs were defined as documentation of: an authorized healthcare surrogate(s), presence of an advance directive, review of previously completed advance directive, and referral or consultation

for palliative care. The mean number of components documented were compared pre- and post-intervention.

Pre-intervention phase: A retrospective medical record review occurred to identify high-risk HF patients seen in the PH clinics between October 2019 and December 2019, and the presence of documentation of GoCCs and four components of GoCCs, as defined below.

Post-intervention phase: A retrospective medical record review, between January 2020 and April 2020, occurred to assess for documentation of GoCCs and the four components of GoCCs among high-risk HF following clinician notification of patients identified as high-risk per calculated one-year mortality risk using an electronic prognostication tool.

Subjects and Setting

This study was identified as a QI project and exemption was obtained from the Office of the Human Research Protection Program at the University of California- Los Angeles. The setting for this study was the outpatient PH clinic within a single Southern California Medical Center. The clinic was staffed by: one nurse practitioner, one clinical nurse specialist, and one cardiology attending physician with a sub-specialty in HF and PH. All clinicians were included in the study. The advance practice nurses and cardiology attending physicians are employees of the Southern California Medical Center. In total, these clinics have an average of fifteen to twenty patients scheduled per week, that are either new consultations or follow ups (see Figure 3).

Medical Record Data

During the pre-intervention and post-intervention phases the primary investigator abstracted medical and demographic (age, gender, race/ethnicity) information from the patient's electronic medical records. Medical information included all medical diagnoses, PH WHO group

classification, presence of an advance directive, and presence of a palliative care referral or prior palliative care consultation. Medical diagnoses abstracted included the following: metastatic cancer, congestive heart failure, dementia, renal failure, weight loss, hemiplegia, alcohol abuse, tumors, cardiac arrhythmias, chronic pulmonary disease, coagulopathy, complicated diabetes, deficiency anemia, fluid/electrolyte disorders, liver disease, peripheral vascular disease, psychosis, pulmonary circulatory disorders, HIV/AIDS, and hypertension. For all patients 65 years and older seen in the PH clinic, the medical diagnoses were used to calculate the Gagne Combined Comorbidity Score (Gagne Score). The progress notes for identified high-risk HF patients, per the Gagne Score, were retrospectively reviewed for documentation of GoCCs (present/absent). This was defined as including any one of the four components of GoCCs: referral for palliative care consultation, completed advance directive and review of advance directive, or identification of the name of the healthcare surrogate. In addition to the presence or the absence of GoCCs, each of the four components were noted to be present/absent.

Gagne Combined Comorbidity Score

Once the medical record data was abstracted, the key elements were used to calculate the Gagne Score. The Gagne Score is a single numerical score that estimates risk of one-year mortality in the adult population living in the community, 65 years and older. It combines the medical conditions from the Charlson Index and Elixhauser comorbidity classification system to improve the mortality prediction model (Gagne et al., 2011). The medical conditions are: metastatic cancer, congestive HF, dementia, renal failure, weight loss, hemiplegia, alcohol abuse, any tumor, cardiac arrhythmias, chronic pulmonary disease, coagulopathy, complicated diabetes, deficiency anemias, fluid/electrolyte disorders, liver disease, peripheral vascular disease, psychosis, pulmonary circulation disorders, HIV/AIDS, and hypertension. Each of the medical

conditions is weighted and the final score is associated with an estimated one-year mortality risk, with higher scores correlating with higher mortality risk. The score can range from zero to greater than nine, with a corresponding one-year mortality risk between 2.4% to 46.8% (see Figure 3). At a score of 3, the patient has an estimated 11.3% risk of one-year mortality. This prognostication tool was evaluated by Yourman et al. (2012) and found to have good discrimination and was well-calibrated for the community-dwelling older adult, defined as 65 years and older.

Procedure

At the start of the intervention the primary investigator conducted a 15-minute in-service to inform all clinicians of the quality improvement project, the indications for GoCCs, and the four components of GoCCs. At the end of the in-service all clinicians received a pocket-sized communication guide. The pocket-sized communication guide provided sample verbal prompts for initiating GoCCs, and listed the four components of GoCCs.

Every week the outpatient PH clinic schedule was reviewed by the primary investigator. All patients receiving care in the PH clinics aged 65 years or older, and living in the community had a medical record data review. Based on the medical diagnoses, as listed above, the primary investigator calculated the Gagne Score then correlated the Gagne Score with the estimated one-year mortality risk. Patients under the age of 65 years or living in a nursing home facility were excluded. A high-risk HF patient was defined as a patient with a Gagne Score of 3 or higher, which correlates with a one-year mortality risk of 11.3% or higher (see Figure 4). On the day of each outpatient PH clinic, individual clinicians received written notification, via secure communication from the primary investigator, of the high-risk PH patients to initiate and document GoCCs in the progress notes for that encounter.

Statistical Analysis

Descriptive statistics were used to describe demographic characteristics of clinician participants and HF patients. To address the first research question (Does pre-identification of high-risk patients, Gagne Score 3 or higher, and a pocket sized GoCCs communication guide, prompt clinicians to initiate and document GoCCs?), Chi-square analyses was used to compare the proportion of high-risk HF patients with documented GoCCs, out of all identified high-risk HF patients that should have had a documented GoCCs. This was done for both the pre- and post- intervention groups.

To address the second research question (If GoCCs are documented, how many components of GoCCs are addressed: authorized healthcare surrogate, presence of advance directive, review of previously completed advance directive, or referral or consultation for palliative care?), descriptive statistics were conducted to determine the presence of each of the four components in the documented GoCCs during the pre- and post-intervention periods. For this analysis the unit of analysis was the documented GoCCs. The percent of the GoCCs that have all 4 components, 3 components, 2 or 1 component were calculated for both pre and post intervention. Then Chi square analyses were conducted to compare the proportion of documented GoCCs that included one, two, three and all four components in the pre- and post-intervention periods. For all analyses, significance level was set a priori at alpha= 0.05. All analyses were conducted using SPSS version 25 statistical package.

Results

The participants for this QI project were three female providers with a specialization in cardiology (26 ± 8.5 years of experience). The participants consisted of a physician, a nurse practitioner, and a clinical nurse specialist.

The pre- and post-intervention patient groups were not statistically different in age, gender, ethnicity, PH WHO group, and Gagne Score (see Table 2). The presence of documentation of GoCCs was significantly increased from pre- to post-intervention (0%, n=0/47 and 88%, n=35/40, respectively, $p < 0.001$). Review of the documented GoCCs, showed that documentation of the four components were variable with improvement primarily in identifying a healthcare surrogate (82.5%, n=33/40) and review of advance directives (47%, n=8/17). In the pre- and post-intervention period there were no patients referred for palliative care consultation. Overall, more components of GoCCs were documented post-intervention than pre-intervention (see Figure 5). During the pre-intervention period there was no documentation of GoCCs and therefore no documentation of any components of GoCCs. In the post-intervention period the documented GoCCs all had at least one (57.5%, n=23/40), two (22.5%, n=9/40), or three (2.5%, n=1/40) components documented.

Discussion

This QI project showed that the use of an electronic prognostication tool to remind clinicians to conduct GoCCs did result in an increase in the number of documented GoCCs. As Bandura's Social Cognitive Theory postulates, personal, behavioral and environmental factors are necessary to support behavior change amongst providers. The findings are consistent with previous findings. In the study by Haley et al. (2016), the intervention was a 10-minute didactic session and electronic reminders for six general medicine inpatient teams, each consisting of an attending physician, one resident, two interns, and a medical student. There was an increase in documented GoCCs from 20.5% for the control group versus 44.6% in the intervention group of 56 patients. Others have also shown electronic reminders for high-risk patients resulted in increase in documented advance directive discussions and completion of advance directives

(Dexter et al., 1998; Heiman et al., 2004). Most recently, use of e-mail reminders to nine medical oncologists, to identify 184 high-risk patients, also resulted in an increase in documentation of GoCCs from 0% to 29% (Karim et al., 2018).

In this QI project, the components of GoCCs that were more commonly present were identification of a healthcare surrogate and review of advance directives. Identification of healthcare surrogates is an essential component of GoCCs as it improves communication regarding patient's preferences which can result in increased compliance with patient wishes, reduction in aggressive medical care at end of life, and increased utilization of hospice (Rose et al., 2019; Brinkman-Stoppelenburg et al., 2014). During the post-intervention period 82.5% of the documented GoCCs had identified a healthcare surrogate. Similar to previous studies, a portion of patients (42.5%, n= 17/40) reported having an advance directive at home but had not shared the advance directive with their healthcare providers (Kaiser Family Foundation, 2017; Gordon et al., 2017). Of these patients, only 8 patients had their advance directives readily available for review. The remainder of the patients requested to bring their advance directive for review during future clinic visits. In addition, these patients were also provided the healthcare facility's patient education Advance Directive packet for review. Overall these findings were comparable to similar studies with unclear impact on clinical outcomes, but the assumption that having GoCCs would ultimately improve patient and family experiences (Haley et al., 2016).

It is also important to note that there were no palliative care referrals made during the pre- and post-intervention period. This finding is similar to previous studies that have shown provider reluctance in referring to palliative care until late in the course of illness (Gadoud et al., 2014; Siouta et al., 2018). Gadoud et al. (2014) evaluated the English registry of primary care medical records and found that 7% of HF patients versus 48% of oncology patients were

receiving palliative care at the end of life. Of the HF patients that were registered, 29% of the HF patients had been registered within one week of their death. Siouta and colleagues (2018) evaluated 22 HF specialists and found that most participants acknowledged that palliative care was either not involved or involved too late in the treatment of HF patients. Karim et al. (2018) found that while GoCCs increased early in the study this was not correlated with an increase in referrals for palliative care over the 16-month intervention. There was no significant change in palliative care referral rates from pre-intervention (36%) to post-intervention (35%). The use of an electronic prognostication tool to identify patients at high risk for one-year mortality and clinician education, may not have been adequate in addressing the needed provider behavior change to initiate palliative care referrals. Additional clinician education focusing on the indication of palliative care for high-risk patients with chronic diseases may need to be considered for future studies. Longitudinal studies to assess GoCCs conducted with the same high-risk patients may also be indicated as palliative care referrals may occur over the course of a series of GoCCs with high-risk patients.

During this QI project there were several limitations that were encountered. By week 9 of the QI project intervention period, a significant public health issue arose. The novel corona virus (COVID-19) pandemic resulted in a national state of emergency, followed by a government mandated quarantine which meant an immediate decrease of all non-emergent face-to-face appointments, to reduce a high-risk patient's risk of exposure. As a result, the original proposed study for 12-weeks pre- and post- intervention was shortened to 9 weeks pre- and post-intervention. Also given the short study time of 9 weeks further studies need to be conducted to evaluate the sustainability of the providers' behavior change. This QI project was focused on one outpatient PH clinic therefore it had a limited participant sample size of three providers. In

addition, limitations from the electronic medical record system did not allow for evaluation of individual provider documentation of GoCCs. Despite these limitations, there was a dramatic increase in the documentation of GoCCs among high-risk HF patients.

Conclusion

The implementation of an electronic prognostication tool was effective in identifying high-risk HF patients (Gagne Score of 3 or greater) for providers to initiate and document GoCCs. There was a significant increase in documentation of GoCCs, addressing all components of GoCCs except for referral to palliative care. It appears that changing provider behavior towards initiating palliative care referrals, for high-risk HF patients, continues to be difficult. The components that notably improved in the documented GoCCs, were identification of a healthcare surrogate and review of advance directives. Further research is indicated to assess the effects of GoCCs on patient outcomes at the end of life. This intervention should also be evaluated in different or additional practice settings. It may also be insightful to evaluate for differences in outcomes between individual providers and also training of the provider. Most importantly, additional studies should be conducted to evaluate the sustainability of maintaining the provider's change in behavior. Despite increasing awareness of the importance of end-of-life care, facilitating conversations and ensuring a patient-centered approach continues to be a difficult topic of conversation between providers and patients. This intervention has demonstrated that GoCCs can be prompted but additional attention needs to be given to addressing the palliative care needs of this high-risk population.

Figure 1. Flowchart of literature review

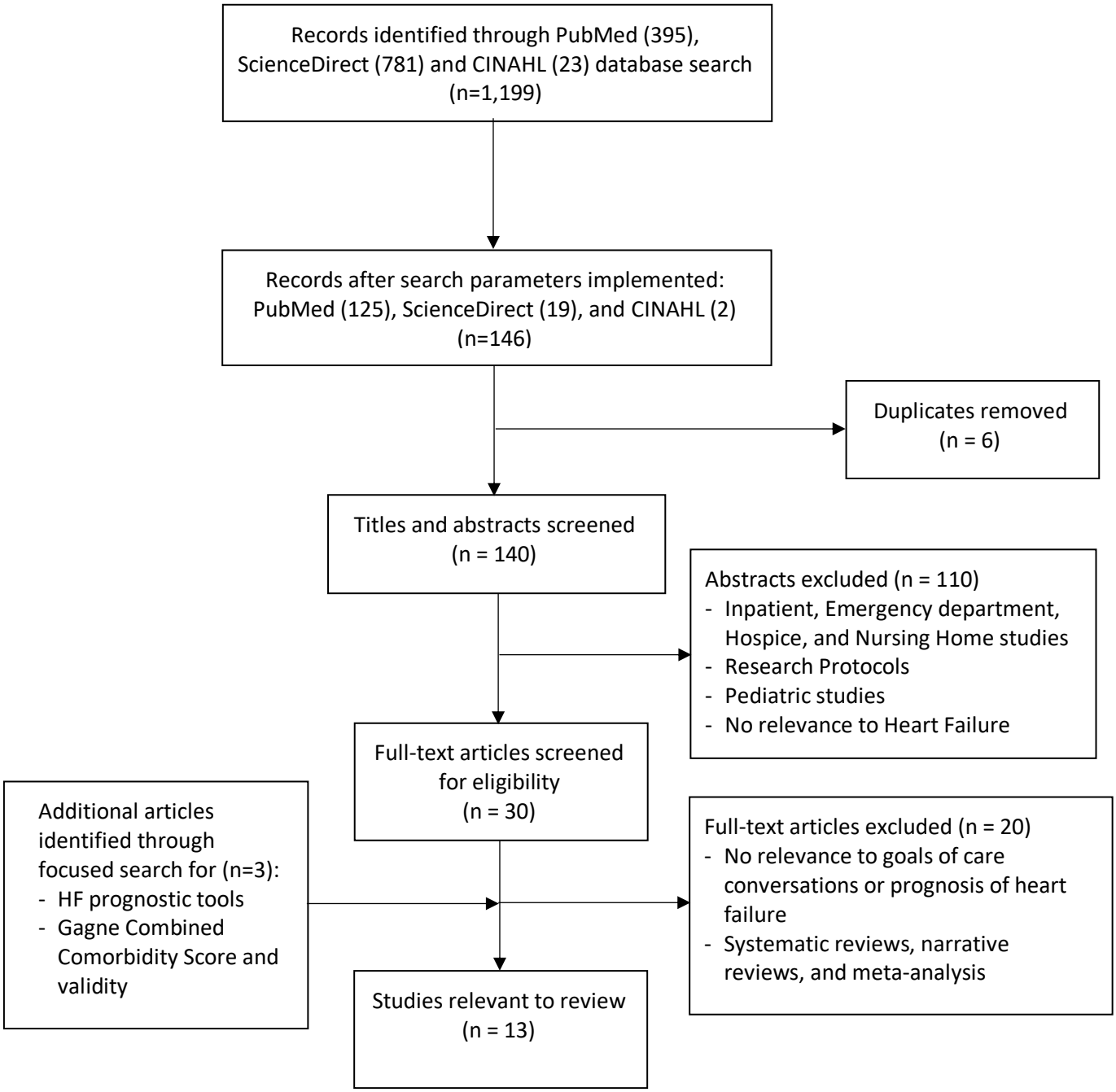

Figure 2. Flowchart of literature review

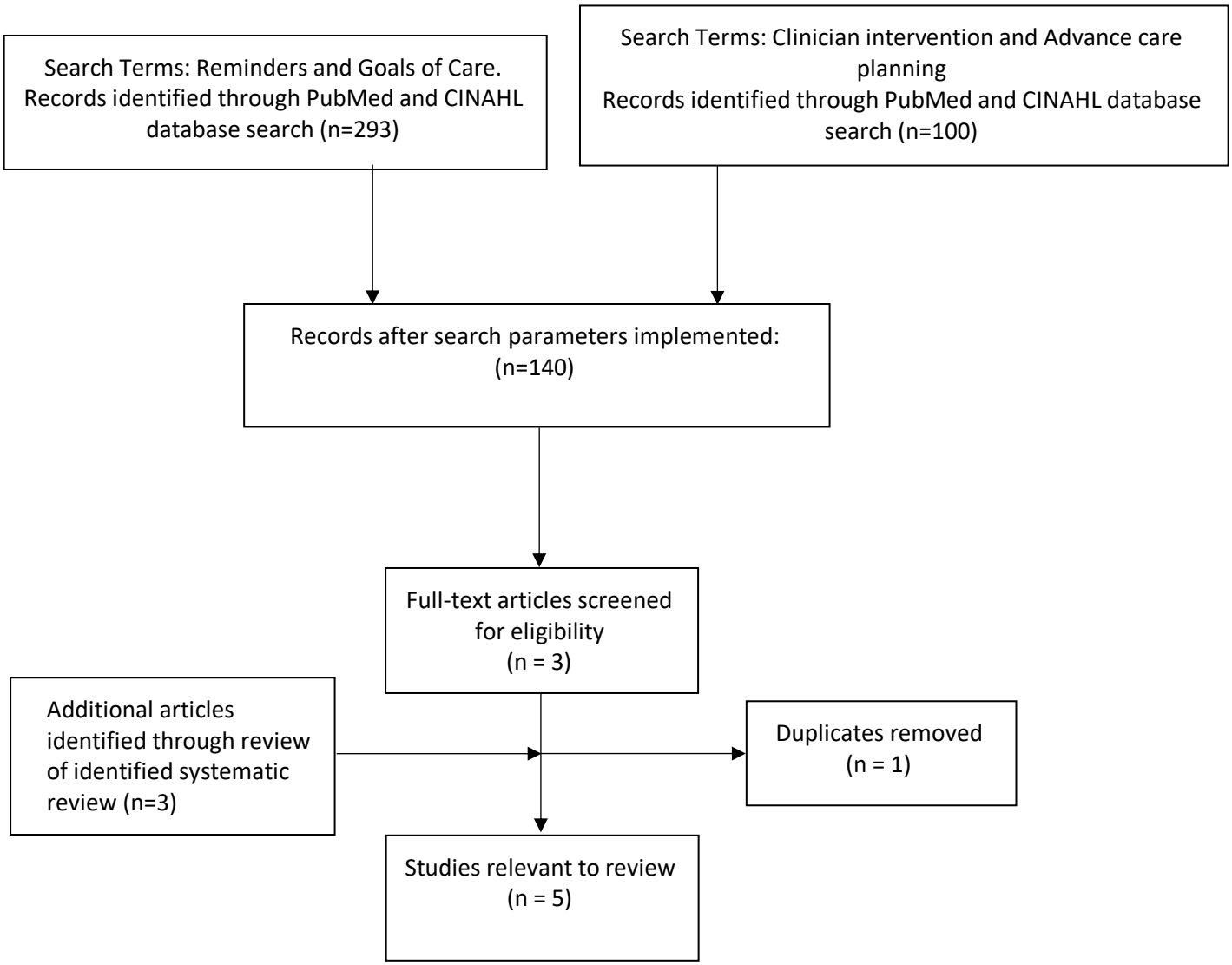

Figure 3. Gagne Combined Comorbidity Score

Medical Diagnosis	Presence of Medical Diagnosis		Score (Yes)
Metastatic Cancer	☐ Yes	☐ No	5
Congestive Heart Failure	☐ Yes	☐ No	2
Dementia	☐ Yes	☐ No	2
Renal Failure	☐ Yes	☐ No	2
Weight Loss	☐ Yes	☐ No	2
Hemiplegia	☐ Yes	☐ No	1
Alcohol Abuse	☐ Yes	☐ No	1
Any Tumor	☐ Yes	☐ No	1
Cardiac Arrhythmias	☐ Yes	☐ No	1
Chronic Pulmonary Disease	☐ Yes	☐ No	1
Coagulopathy	☐ Yes	☐ No	1
Complicated Diabetes	☐ Yes	☐ No	1
Deficiency Anemias	☐ Yes	☐ No	1
Fluid and Electrolyte Disorders	☐ Yes	☐ No	1
Liver Disease	☐ Yes	☐ No	1
Peripheral Vascular Disease	☐ Yes	☐ No	1
Psychosis	☐ Yes	☐ No	1
Pulmonary Circulation Disorders	☐ Yes	☐ No	1
HIV/AIDS	☐ Yes	☐ No	-1
Hypertension	☐ Yes	☐ No	-1
		Total Points:	
		Risk of One Year Mortality	

Points	Risk of ONE YEAR mortality
<0	2.4%
0	3.6%
1	5.1%
2	7.8%
3	11.3%
4	14.6%
5	20.1%
6	24.9%
7	29.5%
8-9	36.5%
>9	46.8%

**Adapted from Gagne et al. (2011).*

Figure 4. Patient Inclusion Criteria

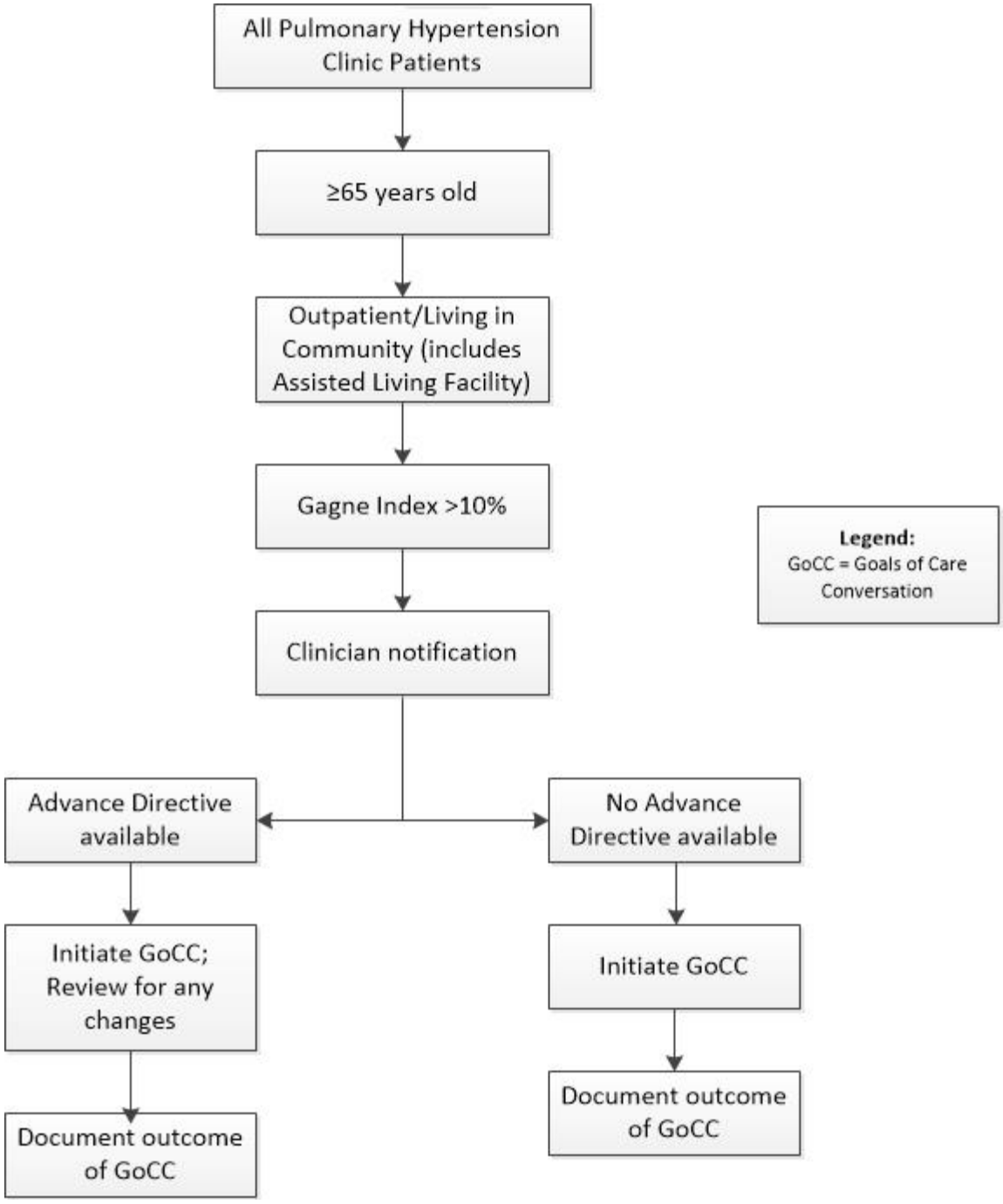

Figure 5. Documented Components of GoCCs

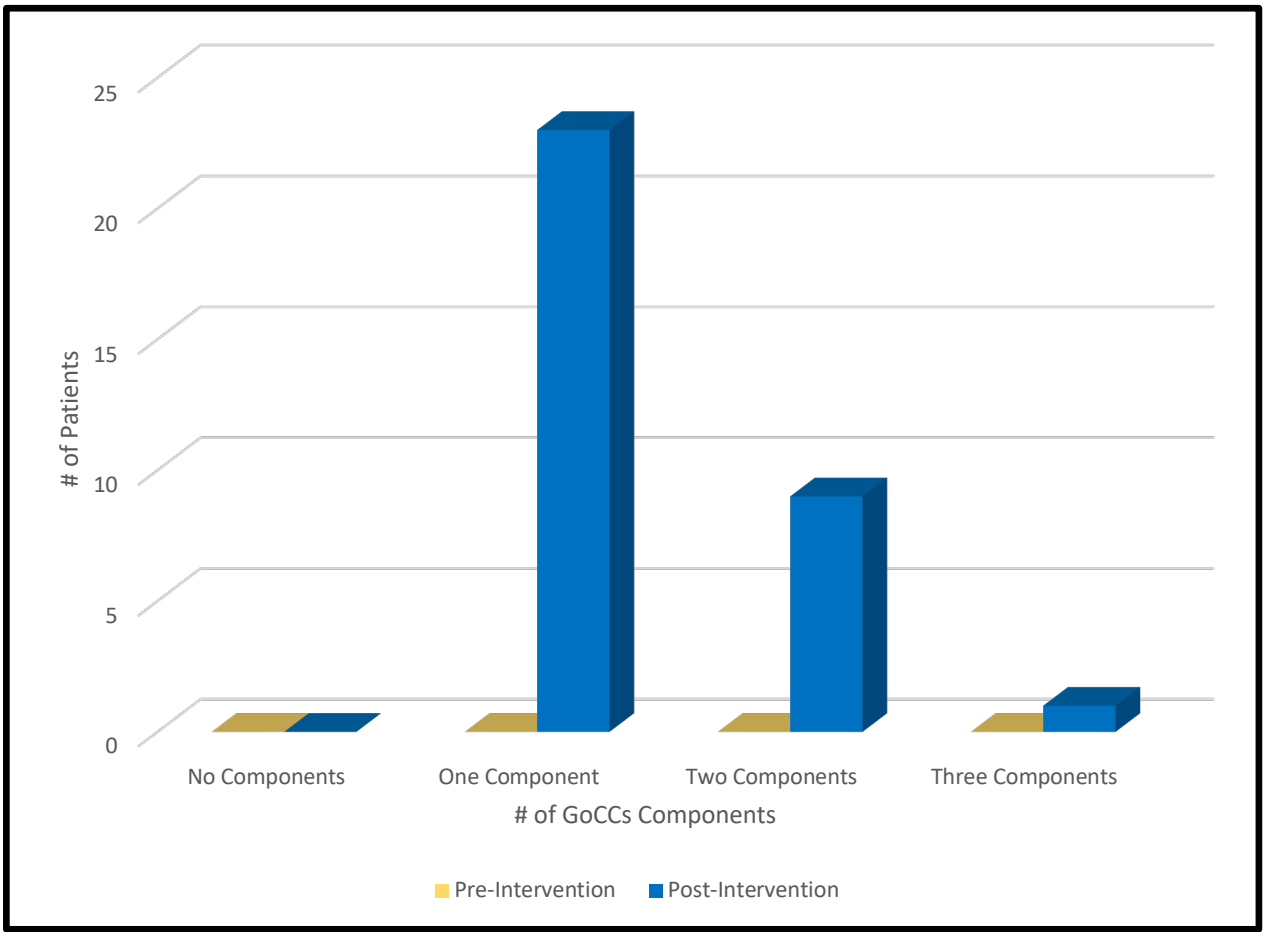

Table 1 Table of Evidence

Author, Year	Purpose	Sample & Setting	Methods, Design, Interventions, Measures	Results	Discussion, Interpretation, Limitations
Studies supporting Goals of Care Conversations with Heart Failure patients					
You, J.J., Aleksova, N., Ducharme, A., Maciver, J., Mielniczuk, L., Fowler, R.A., . . ., & Ross, H.J. (2017). Barriers to goals of care discussions with patients who have advanced heart failure: Results of a multicenter survey of hospital-based cardiology clinicians. *Journal of Cardiac Failure, 23*(11), 786-793. doi:10.1016/j.cardfail.2017.06.003	To assess the cardiology clinicians' perspectives on the different barriers to communication and decision-making surrounding goals of care; and to evaluate the healthcare professionals that should discuss goals of care with the patients and their families.	Setting: Eight teaching hospitals across Canada, in British Columbia, Alberta, Manitoba, Ontario, Quebec, and Nova Scotia between April 9, 2015-October 31, 2015 Sample: 770 of 1024 cardiology clinicians, including cardiologists, cardiology fellows, and cardiology nurses	The DECIDE-HF is a 24-question survey where the participants rate the importance of each statement, on a scale of 1 (extremely unimportant) to 7 (extremely important). Questionnaires were completed via paper or web-based formats. Questionnaire data were analyzed by all cardiology clinicians and also by clinician professional group. Findings were depicted graphically, means, and 95% confidence intervals. Spearman correlation coefficients were used to evaluate the responses between professional groups.	All clinicians identified patients and family members, and their understanding of prognosis and risks vs benefits of various treatments, as the main barriers. Physicians were identified at the most acceptable profession to lead GoCCs but nurses, social workers, and advance practice nurses were also felt to be acceptable for initiating GoCCs and guiding decision making.	While clinicians identified patients and family members as the main barriers it was also noted that physicians did not regularly include prognosis as part of their regular practice. Therefore, it is likely that clinicians' attitudes towards discussing prognosis and EoL may also be a barrier. Tools and communication skills training for clinicians in disclosing prognosis and the uncertainty of HF, may support quality GoCCs. Further research is needed to assess use of common approaches in initiating GoCCs. Limitations: Generalizability given study conducted only in Canada and conducted in teaching hospital settings. Also, the use of a fixed questionnaire may have swayed clinician responses.

Author, Year	Purpose	Sample & Setting	Methods, Design, Interventions, Measures	Results	Discussion, Interpretation, Limitations

Hjelmfors, L., Sandgren, A., Strömberg, A., Mårtensson, J., Jaarsma, T., & Friedrichsen, M. (2018). "I was told that I would not die from heart failure": Patient perceptions of prognosis communication. Applied Nursing Research, 41, 41-45. doi:10.1016/j.apnr.2018.03.007	To evaluate the experiences of HF patients during discussions on prognosis and how these experiences influenced future discussions about prognosis	24 patients with a diagnosis of HF by a cardiologist, with no other major life-threatening disease; all patients were recruited from an outpatient HF clinic of a county hospital in a medium-sized city in Sweden	Inductive and exploratory study design with focus group interviews with 15 patients and individual interviews with 9 patients. Interviews were led by the first and last author with a semi-structured interview guide. Thematic analysis was used to extract the data and associate it with a code, then themes and subthemes were identified. Finalized analysis were reviewed by all members of the research group.	- The message sent
				  - Patient unaware of prognosis due to lack of information provided by clinicians
				  - Inaccurate prognosis, misled to believe HF was not a life-limiting disease
				  - Appropriate delivery and adequate information tailored for the patient
				- Hoping for the best or preparing for the worst
				  - Avoided HF, deferred discussions about end-of-life
				  - Preferred limited information, focused on the positive
				  - Full disclosure with clear information on the illness and prognosis
					The variation in responses from patients highlights the challenges clinicians face when communicating prognosis for HF, it is patient-specific. However, focus on patient education regarding the progression and chronicity of HF can lead to further discussions regarding goals of care.
					The researchers primarily interviewed patient in NYHA Class I-III and viewed this as a limitation, however this patient population is more relevant to the outpatient HF clinic setting. Limitation would be the study was in Sweden and there may be cultural differences that affect patient's views on their medical care. Further research needed to evaluate interventions to optimize patient-clinician communication regarding HF prognosis and goals of care.

Author, Year	Purpose	Sample & Setting	Methods, Design, Interventions, Measures	Results	Discussion, Interpretation, Limitations
Gordon, N.A., O'Riordan, D.L., Dracup, K.A., De Marco, T., & Pantilat, S.Z. (2017). Let us talk about it: Heart failure patients' preferences toward discussions about prognosis, advance care planning, and spiritual support. *Journal of Palliative Medicine, 20,* 79-83. doi:10.1089/jpm.2016.0097	Evaluating patient preferences associated with prognosis, advance care planning, social and spiritual support; to assist clinicians in initiating conversation regarding these issues	Sample: 104 patients with HF receiving care at outpatient HF clinics, seen between July 2007 and November 2009. Setting: Patients recruited from outpatient HF clinics associated with a large urban, academic, medical center in the United States	Convenience sampling approach to consenting eligible patients. Baseline survey to be completed and mailed with a follow up telephone call if surveys not received within 4 weeks. Survey included demographic data, number of admissions, history of HF, in addition to questions regarding advance care planning and social/spiritual preferences. Statistical analysis of the data with descriptive statistics and Chi-square analysis using SPSS software for Mac version 23.	1- Most patients reported discussions with their clinicians regarding expectations of HF (76.5%), prognosis (68%), and surrogate choice (90.3%). Those that had not indicated they would want to have these conversations. 2- While 90.3% of the patients surveyed had identified a surrogate only 63.4% had shared this information with their clinician	Conversations regarding advance care planning are occurring however can still be improved, supported by the positive response from patients that had not had these discussions. Unclear what the barriers were to clinicians addressing advance care planning universally. Also need further evaluation into how these conversations are being documented, role of palliative care referrals in this process, and the patient's perspective of these conversations. Limitations: Survey was completed ten years ago and there may have been changes in the survey responses since that time. There was limited patient participation with half of approached patients declining.

Author, Year	Purpose	Sample & Setting	Methods, Design, Interventions, Measures	Results	Discussion, Interpretation, Limitations
Ambardekar, A.V., Thibodeau, J.T., DeVore, A.D., Kittleson, M.M., Forde-McLean, R.C., Palardy, M., . . ., Stewart, G.C. (2017). Discordant perceptions of prognosis and treatment options between physicians and patients with advanced heart failure. *JACC: Heart Failure, 5*(9), 663-671. doi:10.1016/j.jchf.2017.04.009	To determine if there was a difference in the perception of disease severity between the HF patient and clinician. Also, to evaluate the patient's willingness for pursuing advanced HF therapies and life-sustaining treatments.	Sample: 161 advanced HF patients with a NYHA functional class of III or IV, and their physicians Setting: 11 advance HF ambulatory centers for patients seen between 5/17/2013 and 10/31/2015	At time of study enrollment, the patient and treating HF clinician were surveyed about their perceptions of HF diagnosis on a 5-point Likert scale. Patients were also surveyed on their perception of life expectancy. Data continued to be collected over 24 months, in addition to telephone evaluation at 6- and 18-month to evaluate for endpoints: death, transplantation, or LVAD placement Statistical analysis was performed on SAS version 9.4 software. The researchers used descriptive statistics. Chi-square test of Fisher's exact test was used for categorical variables, and 1-way ANOVA test for continuous variables.	There was a big discrepancy between physician assessment of 1-year mortality (69%) versus patient assessment (14%). In follow-up 38% of the patients experienced one of the endpoints. Of the cohort of patients identified by physician's as high-risk only 51% had a designated healthcare proxy or power of attorney, and only 37% had any discussion with their physician regarding life-sustaining treatments. There was also a mismatch of patient understanding of advanced therapies, with 77% of patients willing to consider LVAD implant yet only half were willing to consider ventilation, dialysis, or feeding tube	The clear disparity between patient and their treating physicians' perception of severity of HF is a barrier to conversations about prognosis and treatment options. Given the percentage of patients that met endpoints at 6- and 18-months, it seems that physicians may overestimate risk while patients underestimate risk. Initiating GoCCs may start with eliciting the patient's perception of illness severity. Limitations: Patients were recruited from HF clinics where they were referred for evaluation for advanced heart therapies. The questionnaires did not define different terminology so responses may be variable based on individual definitions

Author, Year	Purpose	Sample & Setting	Methods, Design, Interventions, Measures	Results	Discussion, Interpretation, Limitations
Gadoud, A., Kane, E., Macleod, U., Ansell, P., Oliver, S., & Johnson, M. (2014). Palliative care among heart failure patients in primary care: A comparison to cancer patients using English family practice data. *PLoS ONE, 9*(11), e113188. doi:10.1371/journal.pone.0113188	Assess the national UK primary care database for inequities in in care provided to HF patients in regards to the recognition of need for palliative approach and the timing of the recognition in relation to the patient's death.	Sample: Identification of 27,689 patients with a diagnosis of cancer or heart failure that died in 2009, that has been receiving care for at least 1-year prior to their death Setting: United Kingdom national primary care database	Patients were separated into "HF only"; "cancer only"; and "HF and cancer." The number of patients, number of patients on the palliative care register, time of registration on palliative care register to death, and sex. Statistical analysis with descriptive statistics on Stata analytic software, version 12.1. Median, interquartile ranges, mean and standard deviation. Differences in distribution were tested with Pearson's chi squared.	For the entire sample studied, 19% were enrolled in the palliative care registry. There was a wide disparity in patients on the HF register and palliative care register (7%); and cancer register and palliative care register (48%). Of the patients registered on the palliative care register within the last year of life was very similar for HF (79%) and cancer (80%) however the timing for which they were entered was significantly greater in the HF at one week prior to death (30%) and six weeks prior to death (50%), compared to cancer patients at one week prior to death (8%) and 6 weeks prior to death (29%)	There was a marked difference in the proportion of HF patients on the palliative care register than cancer patients. Attributed to reluctance and difficulties in discussing poor prognosis of HF given unpredictable trajectory termed as "prognostic paralysis", avoid causing premature alarm. Major gaps despite national recommendations for primary care to coordinate palliative care. Clinicians need further guidance and training on identifying patients and incorporating these discussions in the outpatient setting. Limitations: Review of data inputted into registries therefore always possibly of incorrectly entered information. Potential for inaccuracies on death certificate. Data from 2009 therefore changes may have occurred.

Author, Year	Purpose	Sample & Setting	Methods, Design, Interventions, Measures	Results	Discussion, Interpretation, Limitations
Siouta, N., Clement, P., Aertgeerts, B., Van Beek, K., & Menten, J. (2018). Professionals' perceptions and current practices of integrated palliative care in chronic heart failure and chronic obstructive pulmonary disease: A qualitative study in Belgium. *BMC Palliative Care, 17*, 1-9. doi:10.1186/s12904-018-0356-7	Given the documented evidence that patients with HF and chronic obstructive pulmonary disease (COPD) are less like to receive palliative care, this study examines the perceptions of cardiologists and pulmonologists; and the current practices in Belgium of integrated palliative care for HF and COPD patients	Sample: 22 HF specialists and COPD specialists practicing within a public medical center, outpatient and inpatient, that spoke English. Sample: Phone or in person interviews in different regions of Belgium: Brussels, Flanders, and Wallonia.	Qualitative descriptive study to assess clinician perceptions on integration of palliative care for HF and COPD patients. Total population purposeful sampling of 312 clinicians. Interviews conducted via telephone or face-to-face. 10-question semi-structured interview. Recordings transcribed and independently analyzed based on thematic analysis, then coded with NVivo 11 software.	- Important to discuss prognosis but variation on appropriate timing - No consensus on when palliative care should be introduced due to unpredictability of the disease course; therefore, not utilized or utilized too late - GoCCs are essential but limited by limited time from heavy workload - Continuity with patients is big factor in keeping up with changes in goals/wishes as disease progresses - Variety of medications used to alleviate suffering, not all utilized palliative care - Consensus on importance of advance care planning but no clear guidelines on when and how frequent.	Overall clinicians agreed that advance care planning, ongoing discussions about goals and preferences, and earlier involvement of palliative care are essential in the management of chronic diseases such as HF and COPD, however it is still not occurring. Most likely related to misconceptions regarding purpose of palliative care which can be a barrier within itself when it is brought up in conversation. Targeted education and training still needed. Limitations: Study only in Belgium and relatively small sample size to represent an entire country, and weaker generalizability to other countries given variations in practice and training. Interview was semi-structured with limitations on the participants responding freely.

Author, Year	Purpose	Sample & Setting	Methods, Design, Interventions, Measures	Results	Discussion, Interpretation, Limitations
Wells, R., Ejem, D., Dionne-Odom, J.N., Bagcivan, G., Keebler, K., Frost, J., . . . Bakitas, M. (2018). Protocol driven palliative care consultation: Outcomes of the ENABLE CHF-PC pilot study. *Heart & Lung, 47,* 533-538. doi:10.1016/j.hrtlng.2018.06.012	Evaluate the feasibility of ENABLE CHF-PC (educate, nurture, before life ends: Comprehensive heart care for patients and caregivers)	Setting: Dartmouth-Hitchcock Medical Center in Lebanon, NH and University of Alabama at Birmingham Health System in Birmingham. Sample: 61 patients and 48 family caregivers. Patients with advanced heart failure described as NYHA class III/IV OR AHA/ACC stage C/D; 50 years or older, English-speaking, with access to telephone. Family caregivers identified by patients.	Single arm, two-site feasibility study. Intervention included an in-person outpatient palliative care consultation (OPCC) and 6 weekly telephone sessions to review a curriculum implemented by nurses with specialty training in palliative care. Baseline questionnaires to obtain demographics and baseline medical services utilization. OPCC notes were coded and divided into evaluation, treatment, advance care planning, and care coordination. Quantitative data underwent statistical analysis with t-tests, Chi-square, or Fisher's exact test with SPSS version 24.	39 patients completed OPCC with primary fallout due to no-show, then study withdrawal, then death. Reasons for withdrawal included feeling overwhelmed, not interested, not meeting personal needs, and lost to contact. In the OPCC visit advance care planning was addressed with code status discussions, goals of care discussions, and code status documentation.	The pre-intervention questionnaires were aligned with literature reports, that the patients had to manage significant symptom burden and had unaddressed goals of care needs. The two sites had variation in completion possibly due to distance patient had to travel for the OPCC. For those that did complete OPCC, the findings supported recommendations to introduce outpatient palliative care early with advanced HF patients. Limitations: small sample size, that was primarily one race. Further evaluation needed to examine variations across race, culture, and socioeconomic status.

Author, Year	Purpose	Sample & Setting	Methods, Design, Interventions, Measures	Results	Discussion, Interpretation, Limitations
Klindtworth, K., Oster, P., Hager, K., Bleidorn, J., & Schneider, N. (2015). Living with and dying from advance heart failure: Understanding the needs of older patients at the end of life. BMC Geriatrics, 15, 1-11. doi:10.1186/s12877-015-0124-y	Understand the perspective of the old and very old patients with advanced HF. A qualitative longitudinal study design to evaluate their medical, psychosocial, and information needs at the end of life.	Setting: Two geriatric hospitals located in Hannover and Heidelberg, Germany. Sample: 25 patients that were 70 years and older, NYHA class III/IV, and German speaking.	In-depth interview in the hospital and follow up interviews at patient's home. Interview guides were utilized to evaluate patients' experiences with HF, their main concerns, views on care and treatment, and information about their condition and treatment. Follow up interviews starting at 3-months intervals up to 18-months, max 7 interviews. Iterative analysis on the transcribed recorded interviews, performed using inductive approach from principles of Grounded Theory, on MAXQDA 10 analytical software.	25 patients with an attrition rate of 60% over the course of the study due to refusal for follow ups, changes in mental status, or deceased. The patients did not identify HF as a life-limiting disease, but rather an age-related disease. The experienced increasing anxiety following acute incidents. Their information was limited to what was obtained from their HF providers and did not actively seek information on HF. Most patients indicated their wish to die at home but were not engaged in palliative care services. Most had planned their funeral but not their life sustaining treatment preferences, with some not interested in documentation.	Patient rely completely on their clinicians for information regarding HF disease process, prognosis, and treatment options. The primary concerns were management of symptoms and the disruption the disease causes. Given the dependence the patients have on their clinicians for information it would appear that the clinicians are not addressing poor prognosis associated with HF and end of life issues. Given the goals outlined patients were not integrated with palliative care. Limitations: Small study population focused to two cities in Germany. There was also a high attrition rate through the course of the study therefore less data points over the 18 months as the patient's HF progresses to assess for any changes.

Author, Year	Purpose	Sample & Setting	Methods, Design, Interventions, Measures	Results	Discussion, Interpretation, Limitations
Rogers, J.G., Patel, C.B., Mentz, R.J., Granger, B.B., Steinhauser, K.E., Fiuzat, M., . . . Tulsky, J.A. (2017). Palliative care in heart failure: The PAL-HF randomized, controlled clinical trial. Journal of the American College of Cardiology, 70(3), 331-341. doi:10.1016/j.jacc.2107.05.030	HF is the most common cause of hospitalization in the Medicare population. Evaluation of the impact of an interdisciplinary palliative care intervention, in addition to usual HF management, on overall quality of life for HF patients.	Sample: 150 HF patients at high risk for rehospitalization and mortality Setting: Duke University Medical Center recently admitted HF patients or inpatient HF patients with upcoming discharge.	Hospitalized and recently discharged HF patients were screened for high risk of rehospitalization and mortality based on Evaluation Study of Congestive HF and Pulmonary Artery Catheterization Effectiveness risk score. The patients were randomized into the usual care (UC) arm and the UC plus palliative care intervention (UC+PAL) arm. There was a intervention phase of 6 months but patients were followed in both groups until death or completion of the study. Quality of life was measured by the Kansas City Cardiomyopathy Questionnaire and the Functional Assessment of Chronic Illness Therapy- Palliative Care scale. Descriptive statistics were used for baseline characteristics of the two groups. Linear mixed models were used for primary analysis of the longitudinal data. Kaplan-Meier method and p values estimated the mortality rate.	At 6months 30% of patients had been re-hospitalized and 29% had died, in both arms. Patients in the UC+PAL group had statistically significantly higher scores for the two quality of life questionnaires than the UC group. There was also reduction in depressive symptoms. 12% of the study patients were lost to follow up.	PAL-HF is the first longitudinal randomized, controlled study showing significant clinical benefit of an interdisciplinary approach incorporating palliative care in the management of advanced HF. Validates the recommendations to have a systematic approach of integrating palliative care for HF patients, in the outpatient setting. Limitations is that this was a single-center study thereby limiting its generalizability however there was a diverse mix of patients. This HF setting had already begun to implement palliative care principles in its program.

Author, Year	Purpose	Sample & Setting	Methods Design Interventions Measures	Results	Discussion, Interpretation, Limitation of Findings
Studies supporting Clinician Intervention to increase Goals of Care Conversations					
Doorenbos, A.Z., Levy, W.C., Curtis, J.R., & Dougherty, C.M. (2016). An intervention to enhance goals-of-care communication between heart failure patients and heart failure providers. *Journal of Pain Symptom Management, 52*(30). doi:10.1016/j.jpainsymman.2016.03.018	Evaluate the effectiveness of a patient intervention targeting HF patients with a pre-visit coaching telephone encounter, and a clinician intervention, to increase GoCCs with HF providers, referrals to palliative care services, and completion of advance directives.	Sample: 80 HF patients diagnosed with HFpEF or HFrEF, and Seattle Heart Failure Model (SHFM) Score 95.1±1.6; HF visit in the past six months and future follow up; and spoke English Setting: Outpatient HF clinic in an academic medical center in the Pacific Northwest.	The patient intervention was a telephone pre-visit coaching session with a nurse, a patient activation outline developed from the phone call and shared with patient in addition to education on initiating GoCCs with provider at next visit. The clinician intervention was notification of identified patients for each clinic day. Additional information provided to the clinician was the patient-specific mortality estimates calculated with the SHFM and Kansas City Cardiomyopathy Questionnaire, and communication guide for GoCCs. Evaluation of electronic medical record for documentation of GoCCs. Statistical analysis was performed on SPSS version 19.0 software.	There was a statistically significant ($p < 0.001$) difference in the number of documented GoCCs between the intervention group (58%) and standard of care group (2.6%). The main patient identified barrier was focusing on staying alive rather than discussing death; and the main facilitator was worrying about quality of life in the future. No significant change in referral to palliative care or completion of advance directives. However, there was an increased in patient rated quality of communication with HF provider.	HF patients do not access palliative services early in the trajectory of the disease. The combination of the patient intervention and clinician intervention did facilitate GoCCs as witnessed by the increase in documented GoCCs. The researchers also assessed for patient anxiety and depression, and did not find any increase by initiating GoCCs with patients. Additional research can be done incorporating the caregivers and their influence on GoCCs. Limitations: Small sample size at one facility limits generalizability. Intervention selectively applied versus to all patients.

Author, Year	Purpose	Sample & Setting	Methods Design Interventions Measures	Results	Discussion, Interpretation, Limitation of Findings
Dexter, P.R., Wolinsky, F.D., Gramelspacher, G.P., Zhou, X.H., Eckert, G.J., Waisburd, M., & Tierney, W.M. (1998). Effectiveness of computer-generated reminders for increasing discussions about advance directives and completion of advance directive forms. *Annals of Internal Medicine, 128*, 102-110. doi:10.7326/0003-4819-128-2-199801150-00005	Examine if a computer reminder will motivate clinicians to increase compliance to discuss advance directives with their patients resulting in increase in the number of documented advance directive.	A primary care practice staffed by faculty, fellows, and residents. Four practices each with eight half-day sessions per week. Each session staffed by two faculty and 2-3 residents. Patients that were targeted were patients 75 years and older; and patients 50 years and older with one chronic condition: cardiac ischemia HF, chronic lung disease, cancer, cerebrovascular disease, renal insufficiency, or cirrhosis.	Four randomized categories: control (no reminders), computer-generated reminders of instruction directives, computer generated reminders for proxy directives, and computer-generated reminders for both types of directives. The reminders were incorporated with computer generated reminders that already occur routinely for preventative care, abnormal test results, and drug reactions. All identified patients were interviewed by research assistants immediately post appointment to determine if their clinicians had discussed advance directives with them. Chi-square tests to assess categorical variables and one-way analysis of variance for continuous variables. Logistic regression models.	Enrollment period of 9 months, with 1394 eligible patients. 42 were missed and did not receive immediate post visit follow up, 162 were ineligible (nursing home, deaf, non-English speaking, had advance directive present, and other reason. 86% of Physician encounters with computer generated reminders had advance care planning discussion initiated by the physician. The physicians with reminders for both instruction and proxy directives completed the most forms. Additionally, patients over the age of 75 were more significantly correlated with GoCCs. Presence of GoCCs was highly predictive of completion of advance directive form.	A computer-generated reminder was added to reminders already in place for primary care physicians in outpatient clinics did increase the number of advance directive discussions, followed by completion of advance directive forms by half of those patients. Overall physicians with computer-generated reminders had more GoCCs but also initiated more GoCCs than the control group (no reminder). When advance directives were completed it was to document limitations on end-of-life care preferences. This study was conducted in 1998 when computerized medical records was not available at all healthcare facilities so main limitations were associated with generalizability due to a lack of access to EMR.

Author, Year	Purpose	Sample & Setting	Methods Design Interventions Measures	Results	Discussion, Interpretation, Limitation of Findings
Karim, S., Harle, I., O'Donnell, J., Li, S., & Booth, C.M. (2018). Documenting goals of care among patients with advanced cancer: Results of a quality improvement initiative. *Journal of Oncology Practice, 14* (9), e556-e565. doi:10.1200/jop.18.00031	The overall goal of the study was to improve the quality of care provided to advanced cancer patients by increasing the rates of documentation of GoCCs and to increase the proportion of patients evaluated by palliative care specialists by educating clinicians, sending electronic reminders to clinicians, and by attaching a blue colored form to the paper chart at the time of the visit.	9 medical oncologists at a comprehensive, academic oncology facility in Kingston, Ontario, Canada. The inclusion criteria for the patients were patients with metastatic lung cancer, pancreatic cancer, colorectal cancer, and breast cancer with a life expectancy of <1 year.	Quality improvement study that analyzed data monthly, and plotted on a statistical control chart (*P* chart) to assess for differences across the three improvement cycles: 1- facility guideline for advance care planning, clinician education on GoCCs and documentation, 2- Use of electronic records to identify eligible patients and send electronic notification to clinicians, physical paper reminder at the time of the visit 3- clinicians were provided individualized reports on their GoCCs documentation rate. Publicly posted anonymous scorecard. Documented GoCCs was defined as a blue GoCCs form that was uploaded to the patient's chart. Palliative care consultation was defined as a palliative care evaluation within a year of the visit date.	303 patients were followed, the pre-intervention analysis showed 0% completion of GoCCs forms, with minimal improvement following clinician education, notable improvement with electronic reminder, followed by physical reminder at time of visit. The completion rate of documented GoCCs went from 0% to 29%. The palliative care referral rate increased to approximately 50% after the three quality improvement cycles.	The researchers did not reach their endpoint of increasing GoCCs to 40% and palliative care referrals to 70% but were able to show through the three quality improvement cycles, notable sustained improvements in GoCCs and palliative care consultations for advance cancer patients. As part of the quality improvement a standardized location for GoCCs forms to be scanned and filed in the electronic medical record was established. Patient lists were obtained on a monthly basis versus a per clinic basis. With the endpoint identified as a scanned blue GoCCs form in the patient's chart the researchers were unable to distinguish if there was an attempt to initiate GoCCs but not documented or refused by the patient. Further research needs to be conducted to understand the barriers to GoCCs for this patient population at this facility. Also, retrospective studies to evaluate of sustained or further improvement.

Author, Year	Purpose	Sample & Setting	Methods Design Interventions Measures	Results	Discussion, Interpretation, Limitation of Findings
Heiman, H., Bates, D.W., Fairchild, D., Shaykevich, S., & Lehmann, L.S. (2004). Improving completion of advance directives in the primary care setting: A randomized controlled trial. *The American Journal of Medicine, 117,* 318-324. doi:10.1016/j.amjmed.2004.03.027	Computer-generated physician reminders are effective in promoting primary care screenings, and increasing advance directives (AD). Mailing patients written literature and advance directive forms led to increases in completed AD. This study evaluates the synergistic effect of doing a patient and clinician intervention to increase completion of AD.	The attending faculty physicians from five primary care clinics affiliated with Brigham and Women's Hospital participated. Eligible patients with 70 years or older; or 50 years or older with a chronic illness: AIDs, HIV, cancer, cardiomyopathy, pulmonary edema, CVA, cirrhosis, end-stage renal disease, chronic pulmonary disease, paraplegia or quadriplegia, or amyotrophic lateral sclerosis.	Three arms/groups: physician reminder, physician reminder plus patient mailer, and control. Between 6/2001-1/2002, for the 2 intervention arms an additional computer-generated reminder was added to prompt completion of AD. For the arm including patient intervention the mailer was sent out 1-6weeks prior to their next scheduled primary care appointment. The endpoint was either documentation of an AD in the electronic medical record or a written directive that was returned to the clinic and submitted to the investigators. Demographic and clinical characteristics analyzed with chi-squared tests and Wilcoxon rank-sum test. SUDAAN software used for standard errors for analyses of outcomes. Multivariate logistic regression for differences between the groups.	Control group had 20 physicians from 3 clinics, reminder group had 11 physicians from 2 clinics, and the reminder plus mailer group had 14 physicians from 3 clinics. 1407 patients met inclusion criteria, with 879 assigned to a group. The % of completed AD was 1.8% in the control group, 1.5% in the physician reminder group, and 14% in the physician reminder plus mailer group. Of the 48 completed advance directives, 43 were documented in the electronic medical record correctly, and give handwritten documents were returned to the investigators.	Of three groups, the reminder plus mailed group had the biggest increase in rate of completion of AD. The reminder only group had no statistically significant change. Therefore, the patient mailer may be the effective intervention. The proportion of patients with completed AD was still low (14%). Reasonable for real-life application in clinics as it is a low-cost and simple intervention. Recommendations for systems intervention in electronic medical records to improve physician access to documentation. The end point of the study was completed AD therefore individual progress notes were not reviewed for documentation of AD.

Author, Year	Purpose	Sample & Setting	Methods Design Interventions Measures	Results	Discussion, Interpretation, Limitation of Findings
Haley, E.M., Meisel, D., Gitelman, Y., Dingfield, L., Casarett, D.J., & O'Connor, N.R. (2017). Electronic goals of care alerts: An innovative strategy to promote primary palliative care. *Journal of Pain and Symptom Management, 53* (5), 932-937. doi:10.1016/j.jpainsymman.2016.12.329	Evaluating the effects of electronic alerts in targeted patient electronic medical records, and brief education of clinicians with goals of care pocket care to prompt clinicians to initiate goals of care communication. To increase documentation of goals of care in the medical record and evaluate its effects on patient outcomes such as palliative care referrals, changes in code status, and non-code status care limitations.	Urban tertiary care medical center on the inpatient general medicine services. Six general medicine teams each consisting of an attending physician, one resident, two interns, and a medical student with a daily census of 10-20 patients daily.	Observation period for 4-weeks prior to the intervention. Over the following 4-weeks each team received a didactic lecture (10min) once on how to perform GoCCs and of the study protocol. They all received a GoCCs communication tool as a laminated pocket card. During this period when a patient admitted met criteria an electronic text alert was sent to the resident and attending within 48 hours of admission. The text included a title "Consider a goals of care discussion," a link to the didactic tool, and the criteria that the patient met that prompted the alert. Following the 4-weeks a chart review was conducted to assess presence of documented GoCCs, change in code status, non-code status limitations in care, mention of hospice, or palliative care consultation. Descriptive statistics and Fisher exact tests were used to analyze data with Microsoft Excel and Stata.	Pre-intervention 73 patients met criteria and only 20.5% had documented GoCCs. The intervention group had 56 patients that met criteria with documented GoCCs for 44.6%. There was no statistically significant change in the other variables.	The intervention was easy to implement with a 10-minute didactic session and text alerts. While there was a statistically significant increase in GoCCs there was no change in code status or referral to hospice or palliative care. This study was only over 4-weeks and GoCCs that result in changes in code status or referral to hospice/palliative care consultations may require a multiple conversations or visits. Longer period study is indicated. No assessment of the clinicians to assess for any barriers to initiating GoCCs. The brief didactic and electronic reminder may have been effective in impacting GoCCs in clinical practice. The patient selection was primarily inpatient therefore more research should be conducted to ensure GoCCs are occurring in the outpatient setting prior to an admission.

Table 2. Characteristics of pre-intervention and post-intervention patients

Characteristics	**Pre-Intervention patients n=47**	**Post-Intervention patients n=40**	**P Value**
Mean (SD) or N (%)			
Females	41 (74.5)	33 (65)	0.34
Age in years	75.91 (5.92)	75.80 (6.73)	0.93
Race/Ethnicity: American Indian/Alaska Native	0 (0)	3 (7.5)	0.55
Asian	4 (8.5)	3 (7.5)	
Black	2 (4.3)	3 (7.5)	
Hispanic	5(10.6)	6 (15.0)	
White	30 (63.8)	21 (52.5)	
Other/Declined to Specify	1 (2.1)	1 (2.5)	
PH WHO*Group: I	26 (55.3)	26 (65.0)	0.45
II	2 (4.3)	3 (7.5)	
III	12 (35.5)	6 (25.0)	
IV	5 (10.6)	5 (12.5)	
V	2 (4.3)	0 (0)	
Gagne Score**: 3 (11.3%)	16 (34.0)	8 (20.0)	0.54
4 (14.6%)	9 (19.1)	10 (25.0)	
5 (20.1%)	14 (29.8)	11 (27.5)	
6 (24.9%)	7 (14.9)	9 (22.5)	
7 (29.5%)	1 (2.1)	2 (5.0)	

*PH WHO = Pulmonary Hypertension World Health Organization classification groups where Group I=Pulmonary Arterial Hypertension; Group II=PH due to Left Heart Disease; Group III=PH due to Lung Disease; Group IV=PH due to Chronic Blood Clots (CTEPH); Group V= Idiopathic PH.
**Gagne Score = Gagne Combined Comorbidity Score

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